Reasons for delays in diagnosis of anal cancer and the effect on patient satisfaction

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Abstract

Objective To quantify the time to diagnosis of anal cancer after onset of symptoms, to identify reasons for delays in diagnosis, and to identify the effect of delays on patient satisfaction.

Design Retrospective questionnaire.

Setting Cross Cancer Institute in Edmonton, Alta.

Participants Patients newly diagnosed with anal cancer on their first visit to the centre.

Main outcome measures Timeline from first symptoms to first access to medical care and to diagnosis, and patient satisfaction.

Results Twenty-six patients completed the survey. Although most sought medical attention promptly, 19% waited for more than 6 months. At first visits after symptom onset, a rectal examination was performed in only 54% of patients, a diagnosis of hemorrhoids was given in 27% of patients, and further investigations were ordered in only 54% of patients. If a misdiagnosis of hemorrhoids was made, substantially more visits were required to diagnose the cancer. An average of 3.2 months after the first visit to a physician and 7.4 months after onset of symptoms was needed to obtain a diagnosis. Overall, 28% of patients believed there were no diagnostic delays and 40% of patients thought they were responsible for the delay. Overall, 72% of patients were satisfied with the care they received. Patients who were dissatisfied perceived the delay in diagnosis to be because no action was taken by a physician or the wait was too long for tests or referrals.

Conclusion To reduce delays in diagnosis, it might be important to educate relevant populations about symptoms of anal cancer. In addition, primary care physicians must maintain a high index of suspicion of anal cancer in high-risk populations. Finally, there must be a system-wide increase in access to further investigations through gastroenterologists and general surgeons.

EDITOR'S KEY POINTS

- This study surveyed 26 patients with newly diagnosed anal cancer. On average, the time from onset of symptoms to a diagnosis was 7.4 months (range 0 to 23.6 months, SD 6.8 months). A reduced index of suspicion for malignant disease was demonstrated among primary care physicians, as physicians did not perform digital rectal examinations in almost half the cases; they ordered further investigations in only 54% of first visits; and they gave misdiagnoses of hemorrhoids in 27% of first visits.
- Overall, 28% of patients perceived no delay in diagnosis and 40% assigned the blame for the delay to themselves. Among the patients surveyed, most (72%) were very or somewhat satisfied with their medical care. As expected, more patients who did not believe the medical system was to blame for their delay in diagnosis were satisfied.
- To reduce delays in diagnosis, it might be important to educate the relevant populations about symptoms of anal cancer, and to emphasize to primary care physicians the importance of maintaining a high index of suspicion for anal cancer in high-risk populations and having a low threshold for investigating these patients. Finally, the medical system must improve access and reduce wait times to see surgeons or gastroenterologists for colonoscopies and biopsies.

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Les raisons des retards de diagnostic du cancer anal et les effets sur la satisfaction des patients

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Résumé

Objectif Préciser le temps écoulé entre les premiers symptômes et le diagnostic d'un cancer anal et identifier les raisons des retards de diagnostic et les effets d'un tel retard sur la satisfaction des patients.

Type d'étude Un questionnaire rétrospectif.

Contexte Le *Cross Cancer* Institute à Edmonton, Alberta.

Participants Des patients visitant le centre pour la première fois après un nouveau diagnostic de cancer anal.

Principaux paramètres à l'étude Les dates séparant les premiers symptômes de la première consultation et du diagnostic, et la satisfaction des patients.

Résultats Vingt-six patients ont répondu au sondage. Même si la plupart ont consulté rapidement, 19 % ont attendu plus de 6 mois. Lors de la première visite après les premiers symptômes, seulement 54 % ont eu un toucher rectal, 27 % ont reçu un diagnostic d'hémorroïdes et 54 % ont eu une prescription pour des examens additionnels. Dans les cas où on avait posé un diagnostic erroné d'hémorroïdes, de nombreuses visites additionnelles sont été requises pour diagnostiquer le cancer. En moyenne, il a fallu 3,2 mois après la première visite médicale et 7,4 mois après les premiers symptômes pour poser le diagnostic. Dans l'ensemble, 28 % des patients estimaient qu'il n'y avait pas eu de retard de diagnostic et 40 % croyaient qu'ils étaient responsables du retard, alors que 72 % se disaient satisfaits des soins reçus. Ceux qui ne l'étaient pas attribuaient le retard de diagnostic au fait qu'un médecin n'avait pas posé le geste approprié, ou que l'attente pour les examens ou les consultations était trop longue.

Conclusion Pour réduire les retards de diagnostic, il semblerait important de renseigner les populations à risque sur les symptômes du cancer anal. Il faudrait aussi que les médecins de première ligne maintiennent un niveau élevé de suspicion à propos de ce type de cancer chez les patients à haut risque. Finalement, une amélioration de l'accès aux examens additionnels par l'entremise des gastro-entérologues et des chirurgiens généraux est nécessaire, et ce, à la grandeur du système de santé.

POINTS DE REPÈRE DU RÉDACTEUR

- Cette étude a sondé 26 patients présentant un cancer anal récemment diagnostiqué. En moyenne, le délai entre les premiers symptômes et le diagnostic était de 7,4 mois (entre 0 et 23,6 mois, DS : 6,8 mois). On a observé chez les médecins de première ligne un indice de suspicion trop faible pour une condition maligne; en effet, ils n'ont pas effectué de toucher rectal dans près de la moitié des cas; ils ont demandé des examens supplémentaires dans seulement 54 % des cas lors de la visite initiale; et ils ont posé un mauvais diagnostic d'hémorroïdes dans 27 % des premières visites.

- Dans l'ensemble, 28 % des patients ont jugé qu'il n'y avait pas eu de retard de diagnostic, tandis que 40 % se sont dits responsables d'un tel retard. Parmi les patients sondés, la plupart (72 %) se sont dits très ou passablement satisfaits des soins reçus. Comme on pouvait s'y attendre, il y avait plus de patients satisfaits parmi ceux qui estimaient que le système de santé n'était pas à blâmer pour le retard de diagnostic.

- Si on veut réduire les retards de diagnostic, il pourrait être important de renseigner les populations à risque sur les symptômes du cancer de l'anus et de rappeler aux médecins de première ligne l'importance de maintenir un niveau élevé de suspicion pour le cancer anal chez les populations à haut risque et d'avoir un seuil bas pour investiguer ces patients. Finalement, le système de santé doit améliorer l'accès et réduire le temps d'attente pour voir les chirurgiens et les gastro-entérologues en vue d'une colonoscopie et d'une biopsie.

Cet article a fait l'objet d'une révision par des pairs.
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Anal cancer is a rare malignancy, with 558 Canadians newly diagnosed in 2007. In 2009, 89 Canadians died from anal cancer.[1] Statistics Canada found anal cancer was increasing in prevalence, and this was attributed to increasing incidence, not increasing survival; hence, anal cancer will become a growing public health issue.[2-7]

There is evidence that delays in diagnosing anal cancer exist.[8-10] The delays are anecdotally attributed to the considerable overlap of symptoms with benign diseases, thus rendering this rare disease difficult to diagnose based on history alone. In a small study (N=22), only 23% of presentations were correctly diagnosed by GPs.[10] Carter suggested it is vital for GPs to perform digital rectal examination (DRE) for even trivial anorectal symptoms and then proceed to a speedy referral when indicated.[11]

Delineating the reasons for delays in diagnosis is relevant for several reasons. First, there is some evidence that delays in diagnosis might lead to higher cancer stages at presentation and, therefore, to worse survival.[12] Jensen et al showed delays in diagnosis substantially affected disease-free survival and overall survival.[13] In a study by Johnson et al, later-stage disease was inversely associated with survival, and they suggested that earlier detection might improve survival.[4] In a prospective study, tumour diameter greater than 5 cm, positive lymph node test results, and male sex were associated with worse disease-free survival and overall survival.[14]

The second reason to study delays in diagnosis is that patients are often disturbed by what they perceive as delays in diagnosis or treatment. However, in a study by Schofield, most legal cases based on delays in diagnosis were unsuccessful because it was ruled that the delay did not make a difference in the outcome; that is, the delay did not cause harm.[15] Nevertheless, because of potential effects on survival and patient satisfaction, it is important to study delays in diagnosis, so that delays can be minimized.

The main objectives of this study were to quantify the time to diagnosis of anal cancer after onset of symptoms, to identify reasons for delays in diagnosis, and to identify the effect of delays on patient satisfaction.

METHODS

Setting and participants

This study was conducted from December 2009 to December 2012. Ethics approval was obtained from the Alberta Cancer Board Research Ethics Board. A questionnaire was given to patients newly diagnosed with anal cancer at their first visit to the Cross Cancer Institute in Edmonton, Alta. A research assistant was present to help patients complete the questionnaire and to answer questions.

Design and outcomes measures

The questionnaire had 5 components: demographic characteristics (age, sex, marital status, and education level), relevant past medical history (organ transplants, HIV infection, sexually transmitted infections, anal or genital warts, anal-receptive sex, sexual orientation, and number of sexual partners), timeline from first symptoms to first accessing the medical system (presenting symptoms, approximate date of start of symptoms, length of time to first seeking medical attention, what type of physician was seen, and important outcomes from the first visit [DRE, diagnosis, and further tests or referrals]), timeline from first accessing the medical system until a diagnosis (how many visits were required to make the diagnosis and the date of the diagnosis), and assessment of patient satisfaction (the patients' opinions on the most responsible cause of the delay in diagnosis and overall satisfaction with their medical care).

Electronic medical records were subsequently reviewed for information regarding the date of the diagnostic biopsy, the location of the malignancy (anal margin or canal), the pathologic diagnosis, and TNM (primary tumour, regional lymph nodes, and distant metastasis) stage.

All data were entered into a Microsoft Excel database (Office 2010). Descriptive statistics were obtained for all study variables. Categorical variables were compared with χ^2 tests. A P value less than .05 was used to determine statistical significance. All statistical analyses were conducted using SAS, version 9.3.

RESULTS

Twenty-six patients completed the survey. **Table 1** shows the demographic characteristics and cancer stage at diagnosis of the patients surveyed. The mean age of surveyed patients was 60 years (range 43 to 84 years). There was a higher percentage of women than men (81% vs 19%). **Table 2** shows the risk factors for anal cancer in the surveyed patients.

The most common presenting symptoms were rectal pain, bleeding when wiping after bowel movements, and abdominal pain, which can be typical of both benign disease and anal cancer (**Figure 1**). Patients were allowed to choose more than 1 initial presenting symptom on the questionnaire.

Most patients (65%) sought medical attention within 1 month of symptom onset, but 19% of patients waited for longer than 6 months. A mean (SD) time of 3.2 (3.1) months (range 0 to 9.3 months) was needed after the first visit to a physician to obtain a diagnosis. A mean

Table 1. Demographic characteristics and cancer stage at diagnosis: *N* = 26.

CHARACTERISTIC	VALUE
Mean age, y (median; range)	60 (57; 43-84)
Sex, n (%)	
• Female	21 (81)
• Male	5 (19)
Cancer stage, n (%)	
• I	3 (12)
• II	9 (35)
• IIIA	8 (31)
• IIIB	5 (19)
• IV	1 (4)
Type of cancer, n (%)	
• Margin	2 (8)
• Canal	19 (73)
• Both	1 (4)
• Not stated	4 (15)

Table 2. Risk factors for anal cancer: *N* = 26.

FACTORS	N (%)
HIV infection	2 (8)
Organ or bone marrow transplant	2 (8)
Sexually transmitted infection	3 (12)
Anal or genital warts	6 (23)
Anal-receptive sex	9 (35)
Sexual orientation	
• Heterosexual	24 (92)
• Homosexual	1 (4)
• Bisexual	1 (4)
Self-reported lifetime sexual partners	
• 1-5	15 (58)
• 5-10	5 (19)
• 10-20	3 (12)
• 20-50	1 (4)
• > 50	2 (8)

(SD) of 7.4 (6.8) months (range 0 to 23.6 months) elapsed from the onset of symptoms to a diagnosis (**Figure 2**).

Patients most frequently sought medical attention at their family physicians' offices. The emergency department was the second most frequent place where they sought medical attention. The physician performed a DRE in only 54% of first encounters. Physicians made a diagnosis of hemorrhoids in 27% of first medical encounters, and made no diagnosis in 65% of first medical encounters. Further investigations or referrals were ordered in only 54% of first encounters.

There was a bimodal distribution of the number of visits to a physician needed before a diagnosis was made. Some diagnoses were made very promptly (1 to 4 visits) and some took somewhat longer to make (6 to 8 visits).

When further tests were arranged at the first medical visit, there was a trend toward a biopsy being performed sooner (<5 visits vs ≥5 visits); this finding was not statistically significant ($P = .08$). However, when a diagnosis of hemorrhoids was made on the first visit, significantly more visits to a physician were required to obtain a biopsy (≥5 visits vs <5 visits; $P = .05$).

Figure 3 shows how patients attributed the delays in their diagnosis. Overall, 28% of patients did not believe there was a delay and 40% of patients perceived that they were the most responsible for the delay. In total, 32% believed the medical system was most responsible because it took a long time to see a physician, appropriate action was not taken, or it took too long to obtain further investigations.

Patient overall satisfaction with the medical system with regard to obtaining a diagnosis of anal cancer is shown in **Figure 4**. Most patients (72%) were very satisfied or somewhat satisfied.

The patients who were dissatisfied were those who perceived that the delay in diagnosis was either because no action was taken after seeing a physician or there was a long wait for tests or referrals (**Figure 5**). Patients who required more visits until a diagnosis was made were less satisfied with their care.

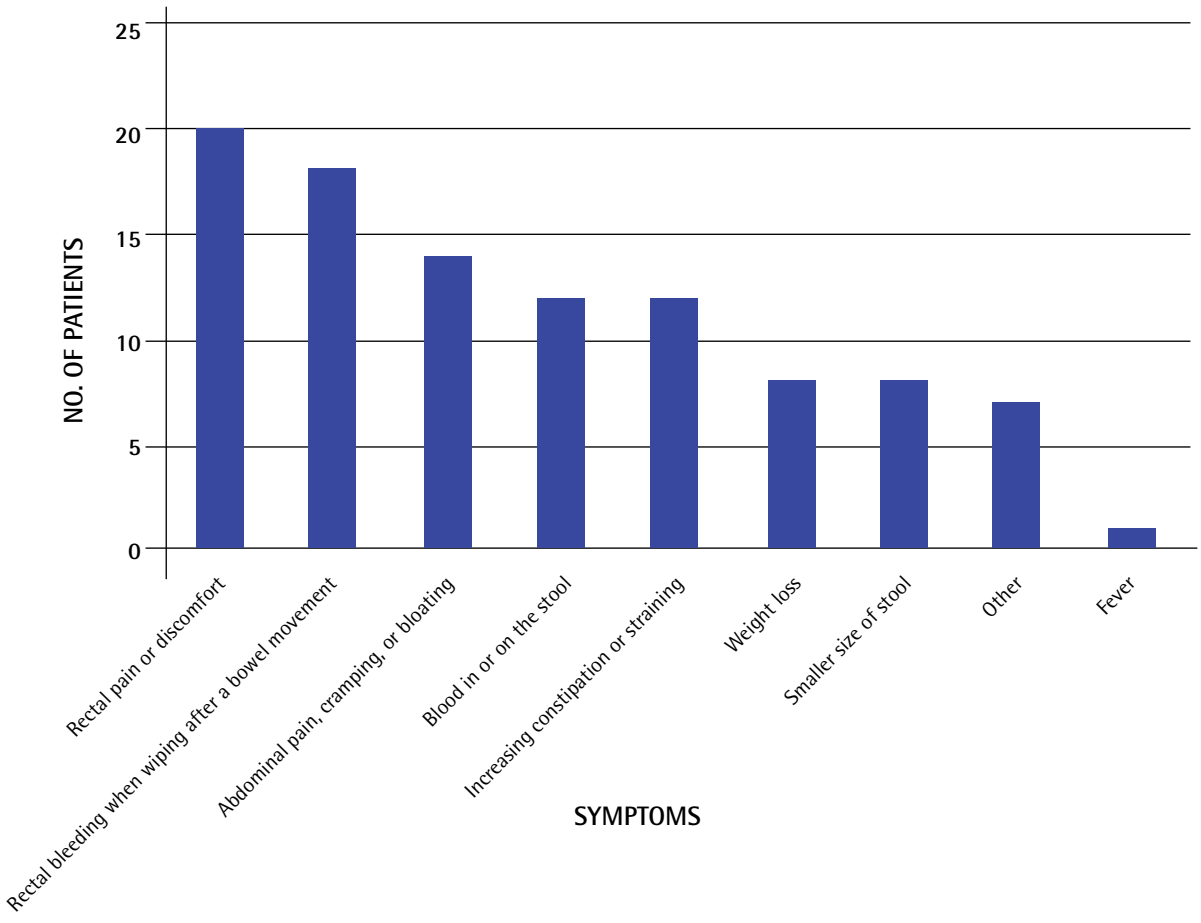
DISCUSSION

There is evidence that delays exist in the diagnosis of anal cancer, and they might adversely affect survival and patient satisfaction. The reasons for the delays are not well understood. This study quantified the time to diagnosis of anal cancer after onset of symptoms, identified reasons for delays in diagnosis, and identified the effect of delays on patient satisfaction.

Most patients sought medical attention within 1 month of onset of symptoms (65%); however, 19% waited longer than 6 months. The average time after the first visit with a physician to reach a diagnosis was 3.2 months (range 0 to 9.3 months, SD 3.1 months). On average, the time from onset of symptoms to a diagnosis was 7.4 months (range 0 to 23.6 months, SD 6.8 months).

Reasons for delays were multifactorial. All of the patients in the study presented with symptoms—most commonly rectal pain or discomfort, and rectal bleeding after bowel movements. This contrasts with the study by Osborne et al, who found that 20% of patients were asymptomatic.[16] Our study suggests that when physicians assess patients with anorectal complaints,

Figure 1. Presenting symptoms



they have difficulty differentiating anal cancer from benign disease, presumably because the symptoms are similar. A reduced index of suspicion for malignant disease was demonstrated in primary care physicians, as physicians did not perform DREs in almost half the cases; they only ordered further investigations in 54% of first visits; and they gave misdiagnoses of hemorrhoids in 27% of first visits. Read et al suggested most anal cancers were visible or palpable for some time before diagnosis, and thus heightened surveillance of high-risk groups with inspection and palpation would be reasonable.[17] The present study demonstrated a significant difference in the number of visits needed in order to obtain a diagnosis when the physician made a diagnosis of hemorrhoids on the first visit (≥5 visits vs <5 visits; $P=.05$). To reduce delays in diagnosis, it might be important to educate the relevant populations about symptoms of anal cancer, and to emphasize to primary care physicians the importance of maintaining a high index of suspicion for anal cancer in high-risk populations and having a low threshold to investigate these patients. Finally, the medical system must improve access and reduce wait times to see surgeons or gastroenterologists for colonoscopies and biopsies.

Patient satisfaction is an important component in evaluating patient care. In this study, 28% of patients perceived no delay in diagnosis and 40% assigned the blame for the delay to themselves. Among the patients surveyed, most (72%) were very or somewhat satisfied. As expected, more patients who did not believe the medical system was to blame for their delay in diagnosis were satisfied with their medical care. Further, patients who required more visits to obtain a diagnosis were less satisfied. Owing to the limited number of patients, it is difficult to interpret the effect of sex and cancer stage on patient satisfaction. Overall, it is important to minimize delays in diagnosing anal cancer because of the effects on patient satisfaction.

Limitations

This study had a small sample (N=26), mainly because

Figure 2. Time from symptom onset to diagnosis

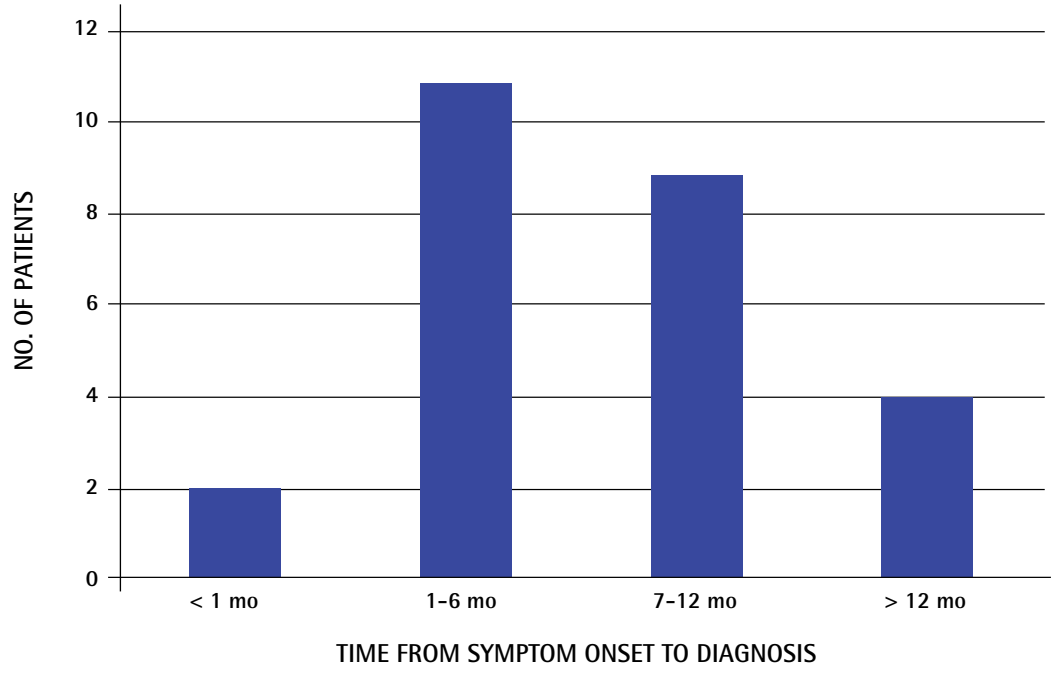
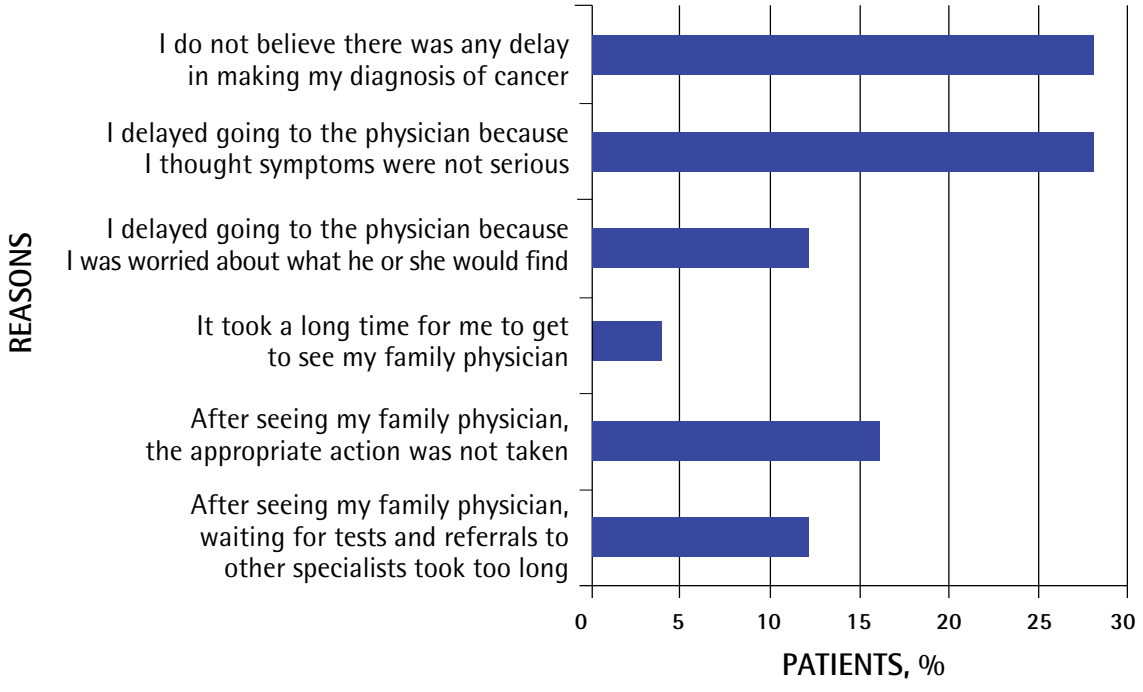


Figure 3. Patient-perceived most responsible reason for delay in diagnosis



anal canal cancer is a rare disease. With the limited data, it was difficult to show statistical significance of delays caused by an initial misdiagnosis of hemorrhoids and the effect of sex and cancer stage on satisfaction. Further, this was a retrospective study, as patients were asked about the timeline from their initial symptoms until they first sought medical attention and had a biopsy. As patients did not complete the survey until

Figure 4. Patient satisfaction with the medical system while obtaining a diagnosis

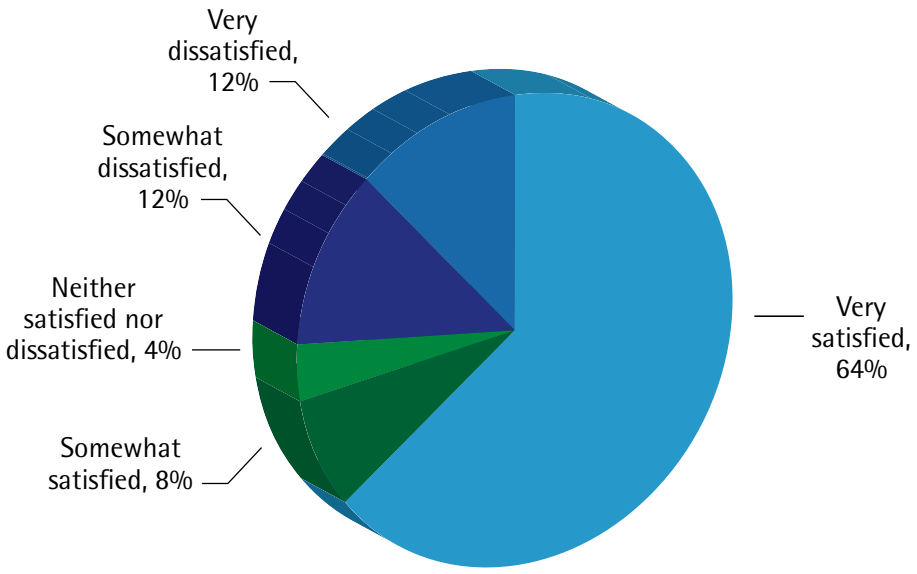
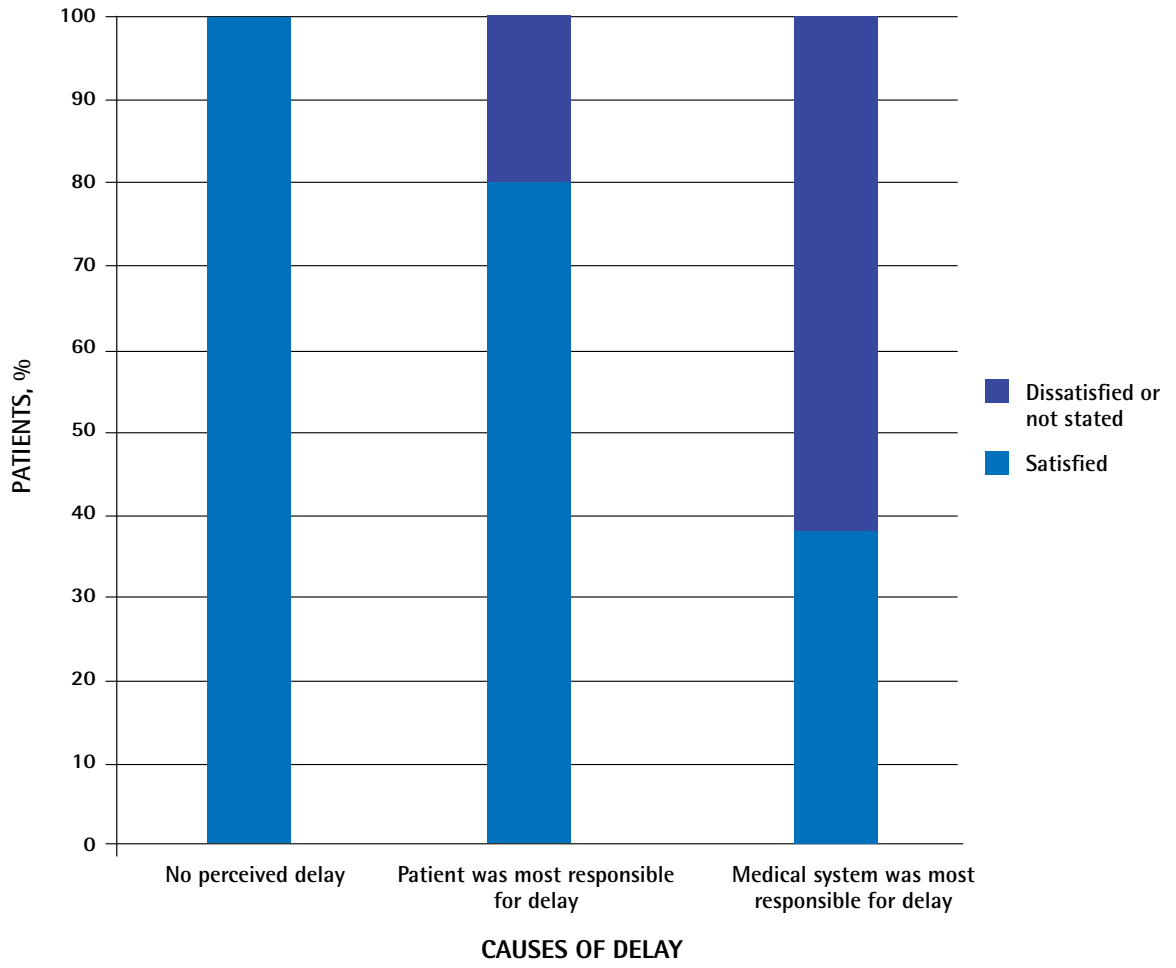


Figure 5. Perceived cause of delay vs patient satisfaction



they were seen at the cancer centre, there is a possible recall bias about how long they waited until they sought care, whether a rectal examination was done, and whether they were given an initial diagnosis of hemorrhoids. This bias was minimized by administering the questionnaire as early as possible (at the first visit to the Cross Cancer Institute).

Conclusion

Minimizing delays in diagnosing anal cancer is important for patient satisfaction, and possibly overall and disease-free survival. In appropriate populations, it is important for physicians not to assume benign disease and to have a low threshold to order further tests or referrals. Further, there must be a system-wide improvement in access to investigations through gastroenterologists and general surgeons. Overall, at the Cross Cancer Institute, most patients with anal cancer were satisfied with the medical care they received while being investigated for anal cancer.

Dr Chiu was a resident in the Department of Surgery at the University of Alberta in Edmonton at the time of the study. **Dr Joseph** is a radiation oncologist at the Cross Cancer Institute and Associate Professor in the Department of Oncology at the University of Alberta. **Dr Ghosh** is Assistant Clinical Professor at the University of Alberta and a research scientist at Alberta Health Services Cancer Care. **Ms Cornand** is a research assistant in the Department of Surgery at the University of Alberta. **Dr Schiller** is Associate Professor in the Department of Surgery at the University of Alberta.

Contributors
All authors contributed to the concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

Competing interests
None declared

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